

June 13-14, 2011 - Wellcome Trust, London, UK

Biomedical Informatics without Borders: Building on Collaborations
NCRI Informatics Initiative and the NCI Joint Conference 2011

Secondary Use Theme

1. Plenary – setting the context of Secondary Use of Health Data

There are many uses of health data in terms of 'Secondary Use' including: health services planning; clinical audit; payment of services and research. This session will explore the context of uses for health data and set the scene for the four other sessions regarding requirements capture, governance (including a patient perspective), standards for data management and interchange and architectures.

2. Requirements capture – what does the various stakeholders want from Health Data?

In this session, we will attempt to look at how health systems have captured the requirements for support to one area that of research. In England the Research Capability Programme spent 8 months with the research community and we will use this case study to review they types of requirements and what can be done to harmonies the future requirements not just for one nation state but globally.

3. Governance arrangements for Secondary Uses

In this session, we will look at the governance arrangements for 'Secondary Use' for health data. This is a hot topic with different territories having alternative privacy laws. We will explore the issues to do with consent and whether opt-out or opt-in to the research use of data are able to be put into operation across health systems. What public fears are there with the use of health data to support research and how can the research and informatics worlds help to dispel the fears in a transparent way?

4. Standards and implementation of standards

We will discuss complexity of standards for research data capture and the level of work being undertaken in various territories, including; the USA, Europe, and Asia, looking at standards driven by national states (BSI – in the UK, CEN in Europe and ISO worldwide).

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The session will try to map what is going and where we can learn from each other and reduce duplication.

5. Architectures

In this session, we will explore the various model technical architectures for implementation of Secondary Uses of health data. The session will consider centralized models of delivery verses distributed model of delivery and the model of cloud computing as an alternative delivery model.